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READER'S GUIDE

Abraham Lincoln's DNA

and Other
Adventures in Genetics

Philip R. Reilly



COLD SPRING HARBOR LABORATORY PRESS

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Abraham Lincoln's DNA *and Other Adventures in Genetics*

Philip R. Reilly

with contributions from *Ann Arbor Reads*



COLD SPRING HARBOR LABORATORY PRESS
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Reader's Guide

Abraham Lincoln's DNA
and Other Adventures in Genetics

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About the Reader's Guide

This guide is designed to stimulate thought and discussion about the topics presented in *Abraham Lincoln's DNA and Other Adventures in Genetics*. It is intended for both individual readers and group discussions, including book clubs, school classes, and other formal and informal gatherings. The guide provides general and chapter-specific questions, and Web resources for further exploration of the issues. The Web resources provide a starting place for following up on the many topics covered in the book. They also supplement and update the chapter-by-chapter bibliography included at the end of the book.

About the Book

Through 24 engaging stories, *Abraham Lincoln's DNA and Other Adventures in Genetics* explores advances in genetics and the social and ethical issues they raise. Topics include the use of DNA in our legal system, genetic engineering and cloning, the role of genes in our health and behavior, and the impact of genetic information on our privacy, rights, identity, and choices. The book was selected for *Ann Arbor Reads* because it presents timely scientific knowledge and is an engaging and accessible read. The book also presents multiple perspectives on the social and ethical issues raised by these controversial topics.

About the Author

Philip Reilly is a lawyer and a physician, and currently CEO of Interleukin Genetics, Inc. in Waltham, Massachusetts. From 1990 to 2000 he was the Executive Director of the Shriver Center for Mental Retardation, Inc. Dr. Reilly has held faculty appointments at Harvard Medical School and Brandeis University. He is currently an Assistant Professor at Tufts University School of Medicine. He is also past president of the American Society of Law, Medicine, and Ethics. He has served on many national committees exploring public policy issues raised by advances in genetics and is frequently asked to comment on these topics by the national media. He is the author of four books and has published more than 100 articles in scholarly journals.

About *Ann Arbor Reads*

Ann Arbor Reads is a community-based initiative to involve all of Ann Arbor in reading and discussing one book during the period from January through March 2003. The program is modeled after *Community Reads* in over 100 cities across the country to promote reading and community-wide discussion of important contemporary issues. *Ann Arbor Reads* is unique in using a work of nonfiction to focus on ethical and social issues raised by advances in the life sciences. This focus is particularly relevant for a city that is at the center of cutting-edge research and development in the life sciences.

Ann Arbor Reads was developed by the University of Michigan's Life Sciences, Values and Society Program (LSVSP), in partnership with Shaman Drum Bookstore and the Ann Arbor District Library. The mission of LSVSP is to engage the University and the general community in study and discussion of the social and ethical dimensions of advances in the life sciences.

To see how you or your organization can participate in *Ann Arbor Reads*, visit www.aareads.org.

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Questions to Consider While You Read

The following questions address general themes that run throughout the entire book.

1. How do advances in genetics affect how we think about our own identity? How do they affect the way we think about group identity? For example, how is our concept of race affected?
2. In what ways might advances in genetics lead to stigmatizing certain individuals, classes, races, or other groups? How might genetics reduce stigmatization of these groups?
3. What aspects of genetic advances may affect you? Your family? Your neighborhood? Your community?
4. Some people have said that scientists and others are “playing God” by pursuing certain genetic technologies. Do you agree or disagree? Why?
5. Should we limit the use of genetic technologies to curing diseases or disabilities, or is it acceptable to use them to improve certain physical or mental characteristics? Do you think that any genetic advances should be outlawed altogether? If yes, which ones and why?
6. As more genetic technologies are made available, such as various tests and treatments, who should be responsible for paying for these services? The government? Insurance companies? Should people be required to pay for the services themselves?
7. How might the development of genetic technologies help or hurt current inequalities in access to health care?
8. Who should decide how various genetic tests and treatments will be used (or not used)? Are policy makers equipped to decide these issues for us? Who else should be involved and why?

General Resources

American Society of Human Genetics

—Nonprofit professional organization for human geneticists, Web site provides educational materials for the general public.

<http://www.ashg.org>

GeneForum

—Nonprofit organization that seeks to promote dialogue and educate people about genome science and its impact on their lives, Web site provides general information on genomics.

<http://www.geneforum.org/>

Genetics Clinics in Michigan

—Wayne State University Web site that provides lists of genetics clinics in Michigan.

<http://www.phymac.med.wayne.edu/departments/Neurology/Genetics.html>

Human Genome Project Information

—Department of Energy Web site with information on ethical, legal, and social issues related to the Human Genome Project.

http://www.ornl.gov/TechResources/Human_Genome/elsi/elsi.html

Kansas University Medical Center—Genetic Education Site

—University Web site with information on the ethical, legal, and social implications of the Human Genome Project.

<http://www.kumc.edu/gec/prof/geneelsi.html>

National Human Genome Research Institute

—Government Web site, includes research, health, and policy and ethics related to the Human Genome Project.

<http://www.genome.gov>

Our Genes/Our Choices—Fred Friendly Seminars

—A three-part PBS series on genetics and privacy, genetics and reproduction, and genetics, behavior, and the law.

<http://www.pbs.org/fredfriendly/ourgenes/>

University of Utah—General Genetics Site

—University Web site educating people about how genetics may affect their lives and society.

<http://gslc.genetics.utah.edu/>

Your Genes, Your Health

—Dolan DNA Learning Center, Cold Spring Harbor Laboratory Web site, provides information about genetic diseases.

<http://www.ygyh.org>

Using DNA to Understand the Past

Author's Comment

I began with the use of genetic information in reassessing the past because I think most people are naturally captivated by history. Witness the national obsession with genealogy! I am fascinated by the notion that the ancient remains of humans (and other organisms) represent a kind of biological time capsule. If we find such capsules, we can use the tools of molecular biology to ask interesting questions about people who lived in another time and place. In writing this part, I focused on historical figures with whom most readers would be familiar. However, if I were writing the book today, I would definitely include more material on the power of comparative DNA analysis to trace the wanderings of the human family since a small group of our ancestors ventured out of Africa about 100,000 years ago. I am astounded that scientists have been able to use differences in mitochondrial DNA to create an evolutionary clock that measures time since the divergence of various groups.

Other Resources

Genetics and Identity Project from the University of Minnesota

—University project, Web site discusses how genetics research may affect racial, familial, and ethnic identity.

http://www.bioethics.umn.edu/genetics_and_identity/

Little People of America Online

—Nonprofit organization Web site that provides support and information to people of short stature and their families.

<http://www.lpaonline.org/>

National Hemophilia Foundation

—Nonprofit organization Web site that provides information for people with bleeding disorders and their families.

<http://www.hemophilia.org/>

National Marfan Foundation

—Voluntary organization Web site that disseminates information to patients, families, and health care providers dealing with Marfan syndrome.

<http://www.marfan.org/>

Discussion Questions

Chapter 1. Abraham Lincoln: Did He Have Marfan Syndrome?

1. If we tested Abraham Lincoln's bone fragments and found he had Marfan syndrome, how (if at all) would it affect your opinion of him?
2. Should there be some sort of privacy right that extends to the dead? Why or why not? If you think there should be such a right, what should it protect? Who would exercise it?

Chapter 2. Kings and Queens: Genetic Diseases in Royal Families

1. If George III had not been burdened with acute intermittent porphyria, do you think that the British colonies in North America might have remained part of the British Empire for much longer than they did?
2. How do you think disclosure that an important government leader was at high risk for developing a severe late-onset disease would affect his or her chances of election?
3. Does a 65-year-old man or woman who is running for an important public office and who knows he or she is at high risk for developing Alzheimer's disease in the next few years have an ethical duty to inform the public? Should this be made a legal obligation?

Chapter 3. Toulouse-Lautrec: An Artist despite His Genes

1. Do you think that Toulouse-Lautrec would have had a markedly different artistic career if he had not been born with the genetic disorder that caused his skeletal problems? Why or why not?
2. Do you think that our society should have laws that forbid marriage between first cousins? If you support such laws, are there other rules about marriage you would like to change? Why?

3. Was Toulouse-Lautrec disabled? Just what is a disability anyway?

Chapter 4. Old Bones: DNA and Skeletons

1. In the debate over the custody and disposition of ancient human remains, whose views should prevail—those of indigenous people who wish to bury them (and who oppose study of them prior to interment) or those of scientists who want to study them?
2. The DNA of any two randomly selected persons on the planet (except identical twins) is 99.9% alike. How might knowledge of genetic similarities and differences lessen or enhance racial discrimination?

The DNA Revolution in the Courts

Author's Comment

Advances in DNA forensics are having a profound impact on our criminal justice system. Frankly, I am astounded at how little public discourse there has been concerning the rapid rise of DNA felon databanks. I personally think that (especially in light of the global war against terror) within the next two decades many developed nations will routinely collect, type, and store a DNA sample for every citizen. The notion of typing a sample to generate a unique genetic fingerprint does not alarm me. The idea that the state could hold a sample of my complete genome and (possibly) subject it to detailed analysis does trouble me. Perhaps as interesting as the questions implicit in my comments is the question, Why have we not as a society debated DNA forensics more fully?

Other Resources

The Dolan DNA Learning Center

—Cold Spring Harbor Laboratory Web site on genes and education; has DNA fingerprinting information.

<http://www.dnalc.org/resources/aboutdnafingerprinting.html>

How DNA Evidence Works

—Commercial Web site that offers information on how DNA is used in the legal system.

<http://www.howstuffworks.com/dna-evidence.htm>

Human Genome Project Information

—Department of Energy Web site on DNA forensics.

<http://www.ornl.gov/hgmis/elsi/forensics.html>

—Department of Energy Web site on genetics in the court system.

<http://www.ornl.gov/hgmis/courts/courts.html>

The Innocence Project

—A nonprofit legal clinic out of the Benjamin N. Cardozo School of Law in New York. Students and attorneys work to free wrongly convicted prisoners using DNA evidence.

<http://www.innocenceproject.org/>

Online News Hour—DNA Data Banking

—A PBS News Hour segment on using DNA evidence in criminal investigations and the ethical issues involved.

http://www.pbs.org/newshour/bb/law/july-dec98/dna_7-10.html

Discussion Questions

Chapter 5. DNA Detectives: The New DNA Evidence

1. When a police officer arrests an individual on suspicion of having committed a crime, should the state have the right to force that person to provide a tissue sample for DNA identity testing? Why or why not? If your answer is yes, should the state be allowed to retain the sample and/or the results of the forensics tests even if the individual is subsequently determined to be innocent of the charge?
2. Currently, forensic DNA samples are used mostly for determining whether two tissue samples derive from the same source. Someday, analysis of DNA sequence might permit detectives to make inferences about the perpetrator's descriptive characteristics, e.g., a tall black male with a receding hairline and diabetes. Should any limits be put on the use of DNA in solving crimes?
3. As part of our Homeland Security initiative, should we take a cheek swab (an easy way to get sufficient cells for DNA analysis) for forensic purposes from every non-citizen entering the United States?

Chapter 6. Cold Hits: The Rise of DNA Felon Databanks

1. Many persons convicted of rape have a history of having committed other crimes, including rape. If we acquired a DNA sample from every person at birth, we would have a powerful new tool to enable us to apprehend the rapist after his *first* crime. Do you favor or oppose universal DNA profiling? Why or why not?
2. Assume you live in a small town. The evidence surrounding a murder committed there suggests the criminal was a local person. The police chief has asked all men from 16 to 60 to voluntarily provide a DNA sample so he can exclude them as murderers. Would you (assuming you are innocent) provide a sample?

Chapter 7. Genes and Violence: Do Mutations Cause Crime?

1. During the next 20 years, we can expect major progress in the field of human behavioral genetics. Imagine that geneticists have identified a common genetic variant (present in 1 of 20 Caucasians) and shown that it is highly correlated with the risk of severe chronic alcohol abuse. Should the state Department of Motor Vehicles be permitted to test applicants for a driver's license for this variant and record the results? If a person is convicted of an alcohol-related crime, how should the fact that he or she carries this variant affect prosecution, defense, sentencing, and parole?
2. Would your opinion about the social uses of this genetic information change if the variant was for the most part only found in Native Americans or African-Americans?
3. There have already been several attempts to use a genetic condition as part of an insanity defense. Do you think that someday genetic data will play an important role in decisions about guilt and innocence?

Chapter 8. Wrongful Birth: What Should the Doctor Know?

1. In the future, we will have access to many more prenatal tests than are currently available. It is likely these tests will range from highly accurate diagnostic tests for uncommon, severe disorders to prognostic tests about risks for childhood disorders, learning disabilities, and diseases such as Type II diabetes that occur later in life. Should the state impose any regulations on the use of such tests? Why or why not? How will a steadily growing foreknowledge of the genetic burdens (and, possibly, benefits) an infant will be born with affect our feelings about pregnancy and parenting?
2. Should a woman who gives birth to a child with a rare genetic disorder be able to sue her physician for failure to tell her about a test that might have predicted the condition during pregnancy? What if it is just one of hundreds of tests? What if the disease will not manifest until adulthood?
3. Do you think an increased number of abortions on genetic grounds will stimulate increased public controversy about the appropriate exercise by women of that privacy right?

Do Genes Make Us the Way We Are?

Author's Comment

In the not too distant future, the gene hunters will identify a small number of genes with variants that predispose individuals to the major psychiatric disorders such as bipolar depression and schizophrenia. I think that this knowledge will eventually create intractable clinical, ethical, and social questions. Consider the profound burden on a parent of being told that an apparently healthy toddler is at high (but not certain) risk of developing schizophrenia in 20 years. How should the tools to derive such facts about people be harnessed? Are there really some risks that it is preferable not to anticipate? I lean toward wanting the information, because I need to believe that I would be able to do something to diminish the risk. However, maybe I am wrong. Perhaps such information would cause serious harm to the parent-child bond.

Other Resources

American Psychological Association

—Nonprofit scientific and professional organization that represents psychology in the United States. Web site provides information for consumers on mental health issues.

<http://helping.apa.org/>

The DNA Files (NPR Radio Program): Genes and Behavior

—NPR program that discusses the science and social issues surrounding behavioral genetics.

<http://www.dnfiles.org/resources/res06.html>

Human Genome Project Information

—Department of Energy Web site on Genes and Behavior.

www.ornl.gov/hgmis/elsi/behavior.html

National Institute of Mental Health, Genetics and Mental Disorders

—Government Web site with more technical information on research on genetics and mental health.

<http://www.nimh.nih.gov/research/genetics.htm>

National Institute on Drug Abuse

—Government Web site with information on drug abuse for students and young adults, parents and teachers, and researchers and health professionals.

<http://www.nida.nih.gov>

University of California Genetics of Absolute Pitch Study

—University study trying to identify the genes that are involved in the development of perfect pitch.

<http://perfectpitch.ucsf.edu/index.html>

Discussion Questions

Chapter 9. Mental Illness: How Much Is Genetic?

1. In the next few years, scientists will find several genes with variants that predispose to schizophrenia. Imagine that there are drugs available to reduce the risk that this debilitating disease will develop in these at-risk gene carriers, but that the drugs sometimes have serious side effects. How would you go about deciding whether to screen children for these gene variants? Given the severity of schizophrenia, should the state compel testing? Given the dangers of the medication, should the state forbid testing? If a child is found to be at risk, may his or her parents refuse the protective medication? Why or why not?
2. Pediatricians, educators, and parents have long proposed “early intervention” as a way to help children with developmental disabilities. We will soon identify gene variants that predispose to autism, attention deficit disorder, dyslexia, and other developmental problems. Should all newborns be tested for these variants?

Chapter 10. Personality: Were We Born This Way?

1. As we learn ever more about the correlation between genetic variations in humans and their personalities, some powerful institutions may be interested in testing for them. For example, might the U.S. military someday develop a panel of genetic tests to ascertain willingness “to take chances” or to measure a tendency to aggression? Might large companies that depend for their revenues on the success of their direct-to-consumer sales force be interested in genetic tests for variants that indicate an extroverted person?
2. Should there be laws forbidding the use of genetic tests in children unless they are intended to identify a disorder that is likely to manifest before age 18 and for which an intervention is available?

Chapter 11. Talent: Nature or Nurture?

1. Someday (many decades from now) we may be able to use genetic engineering to enhance human talents and capabilities. For example, there may be one

(or just a few) gene variant(s) that confers the capacity for “perfect pitch.” (In considering this next question, assume the technological issues have been solved.) If a couple wanted to conceive an embryo via in vitro fertilization (the mixing of sperm with an egg in the test tube) and then use the tools of genetic engineering to have a gene for perfect pitch inserted into the embryo, should they be allowed to do so?

2. If your answer is yes, are you worried about the fact that (as with many aspects of life currently) wealthier people will be much more likely to use these tools than will poor people?
3. Do you think talent of any kind is inherited? Can you point to examples in your own multi-generational family to support your views?
4. How powerful do you think are the forces of heredity in your life? Environment?

Chapter 12. Gay Genes: What's the Evidence?

1. Are there some aspects of human genetics that it would be better not study?
2. If there really is a “gay” gene (subsequent work has not given much support to the original scientific claims), how might a knowledge of that gene be used? Would some couples decide an “affected” fetus should be aborted? Might other couples want to screen for it at birth and intervene to suppress its effects? If a drug was available to do just that, would parents have the right to demand that their children be “treated?” How would the knowledge that a young child is “positive” for the gay gene affect his parents, his school life, the behavior of his peers?
3. Should a woman be allowed to undergo prenatal screening for the gay gene and terminate the pregnancy if the result is positive? Should terminating a pregnancy for “eugenic” reasons be considered legally different from seeking an abortion to end a pregnancy about which the woman has no genetic knowledge?

Genetic Engineering and Nature

Author's Comment

The essential question that underlies the chapters in this section is ancient. Indeed, it is a thematic issue in the book of Genesis: What are our duties as stewards of the earth? There are those who fervently oppose transferring a gene from one species to another, arguing that we should not “play God.” However, each year our species continues to devastate the natural ecology of earth. The rain forest is disappearing, the glaciers are melting, global warming is a harsh reality. Are we not also “playing God” when we unleash millions of tons of greenhouse gases? Do we not have an ethical duty to use our minds to act now to avert the ecological nightmare that will manifest first as extinction of individual species and eventually as wholesale loss of large habitats? Could the cautious, respectful development of genetically modified crops help avert a catastrophe?

Other Resources

Department of Health and Human Services, Secretary's Advisory Committee for Xenotransplantation

—Government Web site with information on xenotransplantation and biotechnology.

<http://www4.od.nih.gov/oba/Sacx.htm>

(*Note:* Xenotransplantation means using live cells, tissues, or organs from a nonhuman animal source transplanted or implanted into a human, or used for contact with human body fluids, cells, tissues, or organs outside of the body that are subsequently given to a human recipient.)

Food and Drug Administration

—Government Web site that discusses the regulation of xenotransplantation.

<http://www.fda.gov/cber/xap/xap.htm>

Genetically Modified Foods

—Commercial Web site that serves as a clearinghouse for information on genetically modified foods.

<http://special.northernlight.com/gmfoods/>

Human Genome Project Information

—Department of Energy Web site with information on genetically modified foods.

<http://www.ornl.gov/hgmis/elsi/gmfood.html>

University of Washington, SCOPE (Science Controversies On-line Partnerships in Education) Research Group

—University Web site, funded by the National Science Foundation, with information on genetically modified foods.

<http://scope.educ.washington.edu/gmfood/index.php>

Discussion Questions

Chapter 13. Genetically Modified Organisms: The Next Green Revolution?

1. How do you feel about consuming food with genetically modified components? Do you think such food should be labeled?
2. Should companies be allowed to sell seed for specialized crops that result in a superb harvest, but in which all the plants are sterile?
3. Should scientists be free to transfer genes between species? For example, should scientists be allowed to move a gene from a food plant that grows in northern Canada into a related strain of food plant that grows in the American south in order to extend the range in which it can be planted?
4. How can we introduce genetically engineered products if there is no way to assess in advance the environmental risks associated with doing so?

Chapter 14. Transgenic Animals: New Foods and New Factories

1. Many people have strong ethical and moral concerns about animal welfare. Should we enact a law forbidding certain aspects of the genetic engineering of animals? For example, should we forbid the transfer of a human gene into another mammal? What if the gene transfer led to production of a protein to treat Parkinson's disease?
2. Are there any circumstances under which you would vote to permit transfer of an animal gene into a human embryo? What if the transferred gene could save a life?

Chapter 15. Endangered Species: New Genes Beat Extinction

1. If we breed a closely related species with an endangered species (such as in the story of the Florida panther), are we saving the endangered species from extinction or finishing it off?

2. Can you think of ways to use the tools of molecular biology to help save endangered species?
3. If we could, should we create frozen embryo banks of as many endangered species as possible?

Chapter 16. Xenotransplantation: Animal Organs to Save Humans

1. Would you accept an organ from an animal to stay alive?
2. Many teams of scientists are working to genetically engineer pigs to be born with kidneys that (if they were transplanted into humans) the human immune system will recognize as human rather than pig. Is it permissible to put human genes in pig embryos to create humanized pig kidneys and then kill the pigs to obtain the specialized organs for donation? Would your answer change if the work was being done on primates?

The Genetic Revolution in Medicine

Author's Comment

For the next 10 to 20 years, our ability to make predictive statements about genetically based risks that contribute to adult-onset diseases such as diabetes and cancer will grow rapidly. I do not think that advances in therapy will grow apace. However, I think that genetic information could become the cornerstone to a new approach to wellness. It is perhaps quixotic, but I dream of a day when young adults will routinely use genetic information to choose lifestyles and diets to reduce their risk of chronic diseases in old age. If I were writing this part today, I would include chapters on pharmacogenetics and nutritional genetics. I am convinced that in 20 years, physicians will frequently choose a medication in part based on the genotype of the patient. The era of “one drug fits all” will be history. I also think that in the future it will be exceedingly difficult to draw the line between medicines and nutritional supplements. Of course, if we really want to improve the public health we must continue to confront the incredible toll caused by cigarette smoking.

Other Resources

Alzheimer's Disease Education and Referral Center

—Nonprofit organization Web site that provides information about Alzheimer's disease and related disorders.

www.alzheimers.org

Centers for Disease Control, D.C. Office of Genomics and Disease Prevention

—Government Web site that provides information about human genetic discoveries and how they can be used to improve health and prevent disease.

<http://www.cdc.gov/genomics>

Cystic Fibrosis Foundation

—Nonprofit advocacy group Web site that provides information about cystic fibrosis. Their goal is to cure and control cystic fibrosis and to improve the quality of life of those who have the disease.

www.cff.org

Human Genome Project Information

—Department of Energy Web site with information on gene therapy.

<http://www.ornl.gov/hgmis/medicine/genetherapy.html>

March of Dimes

—Nonprofit advocacy group whose mission is to improve the health of babies by preventing birth defects and infant mortality. Web site provides information on genetics and diseases.

<http://www.marchofdimes.com/pnhec/4439.asp>

Michigan Breast Cancer Genetics Network

—Nonprofit organization that aims to assist patients in finding information about cancer and cancer genetics, and to inform patients about the experiences of visiting a cancer genetics clinic in the state of Michigan.

<http://www.mi-cancergenetics.org/>

Discussion Questions

Chapter 17. Cystic Fibrosis: Should Everyone Be Tested?

1. About 1 in 28 Caucasians carries a gene variant for cystic fibrosis (a severe genetic disorder that ultimately causes respiratory failure). Persons with one copy of the CF allele are healthy, but if two carriers marry they have a 1 in 4 chance in each pregnancy of having a severely affected child. There is a growing trend to widespread testing of young adults for CF carrier status. How would our society change if all young adults were screened to see whether they carried an allele for cystic fibrosis?
2. Do you think the 1/28 people who are carriers would openly acknowledge this fact? Do you think carriers would usually refuse to date each other? Do you think non-carriers would shun carriers?
3. In many different ethnic groups, some genetic diseases are relatively more common than in the population at large. For example, premarital genetic testing for carrier status for about six different autosomal recessive disorders is now fairly common in the Ashkenazi Jewish community. Some medical schools and commercial labs even offer what they call a “Jewish panel” for tests. Someday there could be panels targeted to several different racial, ethnic, or other defined groups. What information would you want to know before you decided to take such a set of tests?

Chapter 18. Breast Cancer: The Burden of Knowing

1. Is a woman who is born with a mutation in the BRCA1 gene that infers an 80% lifetime risk of developing breast cancer and a 50% lifetime risk of developing ovarian cancer sick or healthy? Why or why not?
2. Should life insurers have the right to require applicants to undergo tests for genes that predispose to colon cancer at an early age?
3. Should individuals who are applying for life insurance have the right to take tests for genetic predisposition to cancer and other late-onset disorders and sequester the results from the insurer?

Chapter 19. Alzheimer Disease: Are You at High Risk?

1. Should a person who knows (on the basis of a genetic test) that he or she is at very high risk for Alzheimer disease be allowed to hide that fact from his or her long-term-care insurance carrier?
2. Given that there is no good treatment for Alzheimer disease, would you undergo a risk assessment test for this disorder? If you would, in what way do you think the results would help you?

Chapter 20. Gene Therapy: The Dream and the Reality

1. Somatic cell gene therapy (usually the insertion of a “healthy gene” into stem cells taken from the patient’s bone marrow and then returned to the patient) is slowly becoming a clinical reality, but there is likely to be a serious risk of severe side effects to the patient for some years. Should parents have the right to consent to high-risk gene therapy in children with severe, incurable disorders?
2. Germ-line genetic engineering refers to the alteration of all of an individual’s cells through the introduction of some new gene into a very early stage embryo. The new gene would even be incorporated into the cells that make eggs or sperm. Can you think of some situations in which you would favor the use of germ-line genetic engineering? What are some possible uses of germ-line gene therapy that you would oppose?

Genetic Technologies and Individual Choice

Author's Comment

During the 1990s, many people became concerned that powerful institutions, such as the insurance industry and employers, would misuse genetic information. Thus far, that has not turned out to be true. Why? We are not yet remotely close to having the kind of predictive powers that might attract unscrupulous persons in such institutions. In addition, we have evolved a rational social policy about the use of genetic information that is now, to some extent at least, embodied in law, regulation, and the public conscience. My real concern is to understand how our rapidly growing ability to acquire large amounts of genetic information will affect the way we think of our fetuses, our children, our neighbors, and ourselves. Is there a new form of eugenics on the rise? Will selective abortion become more commonplace? Will genetic testing someday become a form of biological IQ test?

Other Resources

American Society for Reproductive Medicine

—Nonprofit organization Web site for the advancement of the art, science, and practice of reproductive medicine. Information for patients on infertility, menopause, contraception, reproductive surgery, endometriosis, and other reproductive disorders.

<http://www.asrm.org/Patients/mainpati.html>

Bioethics.Net Section on Cloning

—Web site of the nonprofit organization, the American Journal of Bioethics, provides information on human and animal cloning and bioethics.

<http://bioethics.net/cloning.php>

Michigan Commission on Genetic Privacy Report

—116-page report from 1999 from the state of Michigan. Discusses legal issues and genetics in Michigan.

http://www.michigan.gov/documents/GeneticsReport_11649_7.pdf

Genetic Alliance

—Nonprofit advocacy organization. Web site supports individuals with genetic conditions and their families, educates the public, and advocates for consumer-informed public policies.

<http://www.geneticalliance.org>

National Conference of State Legislatures

—Nonprofit organization that provides bipartisan, national forum for lawmakers to communicate with one another and share ideas. Web site provides information on genetic information and cloning.

<http://www.ncsl.org/programs/health/genetics.htm>

Dolan DNA Learning Center, Cold Spring Harbor Laboratory

—Nonprofit Cold Spring Harbor Laboratory Web site on genes and education. Information from the Image Archive on American Eugenics Movement.

<http://www.eugenicsarchive.org/eugenics/>

Discussion Questions

Chapter 21. Genetic Testing and Privacy: Who Should Be Able to Know Your Genes?

1. Do you favor state-based universal screening of newborns for an ever-growing number of serious treatable genetic disorders? What criteria would you use to decide whether or not to add a certain genetic test to an existing array of newborn genetic screening tests? What protections should the state provide for the test results?
2. Should for-profit companies be allowed to market genetic newborn screening programs directly to consumers? Should the price of such tests be limited in any way?
3. If a doctor discovers that his patient is not the biological child of his presumed father, does the physician have a moral obligation to inform the patient? Why or why not? Is there a significant moral difference between failing to inform the patient about the discovery and deliberately lying in response to a direct question concerning suspicions about parentage?

Chapter 22. Frozen Embryos: People or Property?

1. If a couple divorces and they disagree about the future of embryos that they stored as part of their attempt to deal with infertility, how should the fate of those embryos be settled?
2. Whose interests are controlling, those of the person who wishes to be the parent or those of the person who does not?
3. Should infertile couples who have had children via IVF and who now want to destroy the remaining embryos be allowed to do so?
4. If couples can legally destroy the embryos, should they not be allowed to donate them for research?

5. Is it possible to weigh the interest of the embryos? How? Who should represent these interests?

Chapter 23. Cloning: Why Is Everyone Opposed?

1. Given the apparent promise of embryonic stem cells as new therapeutic tools for severe diseases that affect many millions of people, is it morally permissible to limit severely the use of frozen embryos for therapeutic cloning research?
2. Are there any circumstances under which you would condone human cloning?
3. A new company has been formed that specializes in cloning pets. Is there anything wrong with this?
4. A team of geneticists is thinking about creating a company to create designer pets. For example, consider a house cat with fur the color of the sky on a sunny day. This could eventually lead to the creation of animals with extremely unusual phenotypes (A two-pound mouse? A horse of a different color?). Should this be permitted?

Chapter 24. Eugenics: Can We Improve the Gene Pool?

1. Do you think the state's interest in protecting children is broad enough to permit it to require all couples to undergo extensive genetic testing and receive a "reproduction risk profile" before they can obtain a marriage license? Imagine that the purpose of the law is only to educate the couple. They may do what they want with the information.
2. Can you think of any circumstances that would justify the decision by the state to sterilize an individual without his or her consent?

For More Information and Resources...

The questions and resources provided in this guide represent only a very small portion of the information available on the issues presented in the book. The *Ann Arbor Reads* Web site has an online resource guide to make some of these resources more accessible. On the Web site you will find:

- Age-specific discussion questions and resources
- Resources and discussion questions for groups with special interests, such as:
 - Women and gender
 - Communities of color
 - Religious perspectives
 - Persons with disabilities
- How-to guides for book discussion groups

The Web site also contains further information about *Ann Arbor Reads* and about how you or your organization can get involved. It includes

- An events calendar
- Feedback forms to comment on *Ann Arbor Reads*.

www.aareads.org

